

FISTULA CARE

MEETING THE NEEDS OF WOMEN WITH FISTULA DEEMED INCURABLE: CREATING A CULTURE OF POSSIBILITY



**Report of a Consultative Meeting, Harvard Club, Boston
September 19–20, 2011**



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Individuals working in the field of female genital fistula, many of them providers, persevere in the face of often daunting challenges. It is their willingness to share firsthand knowledge that contributes to our collective wisdom and helps to advance the field. Their perspectives provide critical insight for professional institutions, associations, and ministries of health as they consider how best to use available evidence to create their own standards of care for women with fistula deemed incurable. We would also like to thank the United States Agency for International Development, especially Mary Ellen Stanton and Erin Mielke, for their support of this meeting and for their commitment to fistula prevention and treatment in low-resource settings around the world.

Finally, it is to the women who are living with fistula deemed incurable that we dedicate this meeting report; their courage inspires fistula program stakeholders to create a culture of possibility.



Photo: D. Swanson/EngenderHealth

Meeting Participants

Standing, left to right: Dr. Joseph Ruminjo, Dr. Sohier Elneil, Dr. Lauri Romanzi, Prof. Sayeba Akhter, Ms. Karen Beattie, Dr. Steve Arrowsmith, Dr. Julia VanRooyen, Ms. Erin Mielke, Ms. Gillian Slinger, Dr. Jay Smith, Dr. Sanda Ganda, Ms. Celia Pett

Seated, left to right: Dr. Mark Morgan, Prof. Oladosu Ojengbede, Prof. Serigne Magueye Gueye, Ms. Mary Nell Wegner, Prof. Gordon Williams.

Not pictured: Ms. Bethany Cole, Dr. Gloria Esegbona, Dr. Jennifer Harris Requejo, Ms. Dana Swanson, Ms. Alexa Walls.

Executive Summary

Women in low-resource settings who experience prolonged or obstructed labor may develop an obstetric fistula that results in constant leaking of urine and/or feces. If the woman is able to seek care and if her fistula is not extremely complex, she may have successful repair surgery and return to her life. In other cases, repair may not be possible for several reasons, including:

- The injury is too complex.
- The woman does not have access to medical care.
- Providers do not possess the necessary surgical skills and options for referral or deferral are limited.
- Surgical attempts to repair the injury have failed (sometimes repeatedly).

In these situations, a woman continues to constantly leak urine and/or feces and is unable to live the life she wants. Often, she is socially stigmatized and struggles to make a living and to feed herself.

Historically, the term applied to these women has been *the incurables*. Their condition has been called *inoperable*, *untreatable*, or *unfixable*. All of these labels are devastating and disturbing, suggesting finality and hopelessness. There has been an evolution among the community of providers working with these women to describe them as *women whose fistula is deemed incurable (WDI)*—a slightly more positive description, but one that holds little promise of positive change.

In September 2011, a small group of experts (primarily practitioners) from Africa, Asia, Europe, and the United States met in Boston to consider a range of concerns related to women whose fistula is deemed incurable. The two purposes of the meeting were (1) to consider the spectrum of care needed by these women and (2) to develop recommendations that ministries of health, professional associations, and other key institutions could use as a foundation to develop their own clinical guidelines, standards, and protocols.

Among other recommendations, the group suggested new terminology: *persistent fistula-related pelvic floor disorder* (PFRPFD) or the simpler and more-inclusive *persistent fistula-related disorder* (PFRD)¹. As surgical techniques evolve, as resources increase, and as higher levels of surgical skill become available, a woman currently cast as incurable may, in the future, be cured.

Meeting participants identified issues and made recommendations from four perspectives:

- The client
- The clinical services

¹ The organizers of the meeting used the phrase *women whose fistula is deemed incurable* in the title of the event. During the meeting, the phrase *persistent fistula-related disorder* (PFRD) emerged as preferred terminology; consequently, this report uses this term and the abbreviation in much of the text.

- The program
- Cross-cutting ethical issues central to the preceding perspectives

At the core of the discussion was the recognition that women with PFRD are individuals with agency, able to make informed decisions about their care.

The participants reached consensus in five areas:

- The need to change the current paradigm from one of despair to one of possibility
- A call for social science research to complement clinical research in order to better understand and care for women with PFRD
- The need for mechanisms to engage important stakeholders for obstetric fistula in general and PFRD in particular
- The recognition that key data are essential to evidence-based care and that a registry for women with PFRD may be a valuable tool
- An understanding that the process of empowering women needs to start as soon as possible in the continuum of care in order to help women understand and exercise their options

From these areas of consensus, seven specific recommendations emerged:

1. Share the term *persistent fistula-related disorder* with the larger community of fistula stakeholders for their review and feedback.
2. Ask donors to fund social science research about PFRD.
3. Capture the attention of policymakers by conceptualizing fistula as a chronic, noncommunicable disease.
4. Work with the committee for the International Classification of Diseases (ICD) to categorize obstetric fistula as a notifiable or reportable disease.
5. Commission the design of a patient registry, and pilot test it in several facilities to determine the feasibility of collecting long-term data about women with PFRD.
6. In collaboration with key partners in the obstetric fistula community, convene a small technical working group to discuss a credentialing process for providers and taking meeting recommendations forward.
7. Review existing tools designed to help women make decisions about possible therapeutic options; compare existing tools and explore what helps women to make informed decisions about their care.

Introduction

On September 19 and 20, 2011, 20 experts (primarily practitioners) from Africa, Asia, Europe, and the United States met in Boston to consider a range of concerns related to women whose fistula is deemed incurable. These professionals represented a number of medical and surgical specialties, including urology, urogynecology, obstetrics and gynecology, gynecological oncology, and neurourology. The group also included midwives, a sociologist, and a medical anthropologist.

The group's task was to identify issues and make recommendations from four perspectives:

- The client
- The clinical services
- The program
- Cross-cutting ethical issues central to the preceding three perspectives

At the core of the discussion was the recognition that women with persistent fistula-related disorder are individuals with agency, able to make informed decisions about their care. Client experiences both informed the conversation and served as a reality check for ideas that emerged.

The two purposes of the meeting were (1) to consider the spectrum of care needed by women with persistent fistula-related disorder and (2) to develop recommendations that professional associations, ministries of health, and other key institutions could use as a foundation for professional guidelines, standards, and protocols.

The meeting had four main objectives:

1. To share experiences and draw lessons learned about the magnitude of PFRD and the management of women living with this condition
2. To determine key clinical, ethical, psychosocial, and programmatic issues in the care of women with PFRD
3. To identify gaps, opportunities, and priorities in approaches and strategies for meeting the needs of women with PFRD
4. To advocate for development of rights-based guidelines to be used in the diagnosis of PFRD and the presentation of options to the client; these guidelines would respect clinical, cultural, and continuum-of-care perspectives in low-resource environments

No single body, institution, or facility can meet the full range of needs of women with PFRD. Therefore, the field of fistula care must foster and develop a better understanding of partnerships that include not only ministries of health and professional associations but also additional sectors, including nongovernmental organizations that provide social services, training in income generation, and other kinds of care.

Background

Women in low-resource settings may experience obstetric fistula from prolonged/obstructed labor or traumatic fistula from sexual violence, resulting in constant leakage of urine and /or feces. If the woman is able to seek care and if her fistula is not extremely complex, she may have successful repair surgery and return to her life. In other cases, repair may not be possible for several reasons, including:

- The injury is too complex.
- The woman does not have access to medical care.
- Providers do not possess the necessary surgical skills and options for referral or deferral are limited.
- Surgical attempts to repair the injury have failed (sometimes repeatedly).

In these situations, a woman continues to constantly leak urine and/or feces and is unable to live the life she wants. Often, she is socially stigmatized and struggles to make a living and feed herself.

Historically, the term applied to these women has been *the incurables*. Their conditions have been called *inoperable*, *untreatable*, or *unfixable*. All of these labels are devastating and disturbing, suggesting finality and hopelessness. Among providers who serve these women, terminology has evolved over time with many using the phrase *women whose fistula is deemed incurable*. This description is slightly more positive, but it still holds little promise of positive change. There are no standardized guidelines and protocols for the care and management of women whose fistula is deemed incurable.

For treatment and overall management, the 2006 publication by WHO—*Obstetric Fistula: Guiding Principles for Clinical Management and Programme Development*—is an excellent resource as are a variety of technical textbooks and experienced individual clinical trainers. Yet the challenge remains how best to standardize care based on evidence not only for routine repairs but more so for PFRD.

Additionally, although most fistula care occurs in low-resource settings, differences in culture, gender dynamics, ethnicity, and politics make it difficult to develop universal minimum standards of care. A course of treatment that works in one setting may not in another for reasons beyond the availability of resources or clinical and surgical capabilities.

Fistula surgery happens in a variety of settings: standalone fistula centers, semi –detached fistula units within larger hospitals that provide routine services, facilities that offer fistula services integrated with other services, institutions that provide periodic services offered by visiting surgeons, and outreach camps that help address a backlog of clients. In all instances, the services offered depend on the skill of the surgeons involved. There is rarely,

if ever, the opportunity for a second opinion if a woman and her family are interested in seeking one.

Moreover, PFRD occurs for at least three reasons:

- Damage to tissues and organs is so severe that the fistula cannot be closed despite surgery
- Multiple surgical attempts to close the fistula may have proved futile.
- Surgery has successfully closed the fistula, but the woman has persistent residual incontinence from various causes.

In high-resource settings, the woman may have both surgical and nonsurgical options. In other settings, some of those options may not be available. Also, the choices offered may not be culturally or personally acceptable to women or their families. Regardless of the setting, the woman may require long-term continuous care that is not readily available.

Considering the background information described above, the experts who met in Boston were determined to identify areas of consensus on which to base minimum global standards for the treatment and care of women with PFRD. Participants went beyond describing surgical and nonsurgical options for treatment. They also discussed what it means for women with PFRD, who usually lack formal education, to make an informed choice within the context of fragile health systems where counseling services, if they exist at all are minimal.

Definitions

Before the experts convened in Boston, the organizing committee surveyed the participants on core issues, including the definitions of *incurable* and *success* as these terms relate to the management of PFRD. Not surprisingly, there were as many definitions as there were respondents. In general, however, definitions of *incurable* usually encompassed a history of multiple failed surgeries and an inability to close the fistula and restore the woman to continence. One major repair site, the Hamlin Fistula Hospital in Addis Ababa, has defined ‘*multiple attempts*’ more specifically to mean two repair attempts performed by the most senior surgical team at that facility; the institution’s medical review board must review and give consent for any additional repair attempts.

At the meeting, participants agreed on a conditional definition of *incurable* that is absolute or relative depending on clinical and contextual characteristics:

- Absolute limitations to success of surgical repair due to the complexity of the condition (i.e., a fistula that even the most highly skilled fistula surgeon working in ideal conditions could not repair)
- Relative (or contextual) limitations due to lack of resources (logistical, financial, human) or the cultural unacceptability of the proposed treatment

The definitive clinical characteristics of incurable fistula remain the subject of debate, but participants agreed that the following features are usually involved:

- Severe scarring/Dense fibrosis
- Extremely poor surgical access caused by factors other than scarring
- Cloaca
- Absent urethra
- Extensive damage to bladder neck
- Absent or extremely reduced bladder capacity (with the caveat that if the hole can be closed, it is not too difficult to restore capacity by augmentation with ileum. Some women will then need to learn self-catheterization, which does not require expensive supplies.)

The group acknowledged that some or most of these clinical characteristics may be influenced by contextual factors, such as:

- Timely availability of the highest level surgical skills as well as supportive skills (e.g., nursing care, counseling, peer support)
- Availability of functional and timely referral
- Other systemic issues (such as availability of labs, equipment, supplies, and follow-up care)
- The acceptability of available options to the individual, the family, the community, and the culture
- Multiple previous unsuccessful repair attempts

Participants voiced concern about the extensive impact of relative limitations on therapeutic options for women. In well-resourced settings, some fistulae currently classified as incurable could be successfully repaired. In some contexts, urinary diversion, with all its complexities and life-long follow-up requirements, may be the only surgical option. As advances in surgical repair techniques and effective patient follow-up are made, some women who currently have a fistula considered incurable may have an opportunity for successful repair in the future.

The definitions of *success* provided by participants typically included two characteristics:

- Closing the fistula
- Eliminating stress and other residual incontinence

In addition, the woman should, ideally, be able to have normal sexual and, if at all possible, reproductive function; this standard is rarely achieved among women who have especially complex fistula. Some participants expanded the definition of *success* to encompass the repair of other injuries sustained. The group could not reach consensus on whether a satisfactory alternative procedure, such as a urinary diversion, could also constitute success.

Literature Review

Before the meeting convened, the organizers surveyed the literature about incurable fistula. The review revealed that there is very limited peer-reviewed material on incurable fistula, particularly relating to client perspectives, psychosocial support, and reintegration. Meeting participant Dr. Gloria Esegbona has undertaken an important peer-reviewed publication on client perspectives, findings from which she shared with the group at the meeting.² Dr. L. Lewis Wall and Dr. Steven Arrowsmith have stressed that good data are a baseline requirement for improving clinical practice; furthermore, they believe that gathering such data is a moral imperative so that the field of fistula care can move from “eminence-based medicine,” deriving from individual authority, to evidence-based medicine deriving from reliable data.³

What literature exists is dominated by a small number of practitioners who have concentrated their efforts on the ethical implications of complex surgery in low-resource settings and the perils of “fistula tourism.” While providers who have worked on PFRD for years have a wealth of experience, little organized attention has been given to:

- Professional networking
- Creation of universally accepted definitions
- Establishment of guidelines and standards to help other professionals assist clients with PFRD

Client Perspectives

To help participants understand the day-to-day realities of clients with incurable fistula, Dr. Gloria Esegbona showed a short video of interviews with Nigerian women who have PFRD; she then presented findings from her work done in collaboration with the Fistula Foundation of Nigeria (FFN) and the International Society of Obstetric Fistula Surgeons (ISOFS). Additionally, a small working group discussed gaps and made recommendations from a client perspective.

Considerations

The woman’s opinions about available treatment options and possible outcomes should frame the discussion about interventions. Providers should recognize that “one size does not fit all.” In the words of one meeting participant, “We have got to figure out how to *individualize* the woman.”

Among women interviewed through FFN, economic concerns have been just as important as perineal hygiene, comfort, pads, and nutrition. A major (but not frequently discussed) issue

² Aliyu, F., and Esegbona, G. 2011. Living with obstetric fistula: A patient’s journey. *British Medical Journal* 342:d2881.

³ Wall, L.L., and Arrowsmith, S.D. 2007. The “continence gap”: A critical concept in obstetric fistula repair. *International Urogynecology Journal* 18(8):843–844.

appears to be the number of women with incurable fistula who resort to commercial sex work to earn a living. (Similarly, HIV risk is usually not discussed when determining fistula care priorities, rendering women who undertake commercial sex work especially vulnerable.) In Boston, meaningful income-generating training emerged as a reintegration priority.

Some women have reported that, if they had to choose, they would rather have a functional vagina (*hanya* in Northern Nigeria) than a closed fistula resulting in the inability to have vaginal intercourse (*ba hanya*). For others, stopping the leaking may be the most important priority.

Understanding nonsurgical options and learning how to maintain personal hygiene are critical to the woman with PFRD. Some participants described one option: Jika pads, which women can make themselves using super-absorbent, odor-minimizing bamboo fiber at the center and soft material on the outside. Using Jika pads is preferable to changing rags 10–12 times a day and managing the rashes and other skin irritations that can result. The materials used in Jika pads can also be used to produce sanitary pads and infant diapers, a potential income-generation activity for women.

Treating conditions such as dermatitis, foot drop, and contractures and providing physiotherapy were cited as important needs.

Gaps and Barriers

In most fistula care programs, no platform exists for women to exchange information, make their needs known, and inform program design. This gap affects clients, providers, facilities, and communities. Sometimes the services offered do not match what women want, and nonsurgical options are not discussed.

Often women with PFRD have little understanding of both the condition and the proposed clinical solutions. When discussing surgical options that would significantly alter the woman's anatomy and body image, providers must ensure that she understands the proposed procedures and the potential clinical and social outcomes. A woman considering any type of urinary diversion must know where any new scars or ostomies will be located and must understand how she will urinate and/or defecate after the procedure. Creating an ostomy merely moves the hole from the vagina to the abdomen; it does not solve the problem of PFRD. In the case of ureterosigmoidostomy, it may be culturally unacceptable for the woman to empty both the bladder and the bowel from the same opening.

Women often have no place to go after a failed surgery. Many end up living around the hospital as they try to figure out next steps regarding their health, relationships, and income generation.

There is little information on what happens to women with PFRD, where they are, or what they need over time. Long-term outcomes are unknown, and data on key issues such as survival, nutrition, hygiene, psychosocial support, motor skills, vaginal stenosis, sexuality, and fertility are missing.

Dr. Gloria Esegbona mentioned that ISOFS was preparing clinical guidelines for fistula deemed incurable; the proposed Standard 5 within those guidelines focuses on how to achieve client-centered outcomes, including the following: making the diagnosis, counseling the woman, categorizing types of urinary diversion, and helping with reintegration. The guidelines will also discuss women's needs in relation to managing incurability, monitoring, and follow-up. At the time of the meeting, the ISOFS draft had not yet been completed or shared.

Clinical Perspectives

Over the course of the meeting, participants offered clinical perspectives on the continuum of care, ranging from “do nothing,” (in line with the medical principle of ‘first, do no harm’) to nonsurgical options, to surgery, including different types of urinary diversions and other complex procedures (e.g., neobladder, neovagina, neourethra with or without sling, bladder augmentation). Dr. Steven Arrowsmith, Dr. Sanda Ganda, Prof. Serigne Magueye Gueye, Dr. Mark Morgan, Prof. Oladosu Ojengbede, Dr. Jay Smith, Dr. Julia VanRooyen, and Prof. Gordon Williams explained the role of various options and described the resources needed to perform each procedure safely and successfully. A small working group also discussed clinical perspectives. (See Appendix C for further details.)

Considerations

Noting the complexities of the clinical options, Dr. Steven Arrowsmith said that the choice often is made in daunting environments that lack skilled operating room staff, laboratory facilities, or the ability to provide follow-up care. Given the context, the surgeon must make a judgment about whether it is wise to proceed with a specific procedure. He cited the constant reminders of failure in “the cloud of women hanging around a facility whose needs have not been met by surgery and who are ever hopeful that there are still clinical avenues to explore.”

Explaining the array of urinary diversion procedures, Dr. Julia VanRooyen discussed the feasibility of the choices in different settings. In her remarks, she raised the question of possible systems (1) to identify providers who are competent to provide repairs and (2) to specify management protocols for fistula deemed incurable.

Dr. Sanda Ganda noted that patients in Niger rarely consent to urinary diversion, a situation that has been exacerbated by poor outcomes, including death, in some procedures performed by visiting surgeons. Because many women seeking repair know about these cases, they are reluctant and fearful. Dr. Ganda stressed the continuing need to monitor patients who have had complex procedures, especially for sequelae that require immediate follow-up care. When clients live in remote areas, monitoring and follow-up are especially difficult.

Dr. Mark Morgan described a urinary diversion procedure that uses a detubularized sigmoid pouch (Mainz II). Based on his experience from more than a dozen missions to Eritrea, Dr. Morgan believes that this technique can be effectively used, with low perioperative morbidity and mortality; special equipment and appliances are not necessary. He cited overall patient satisfaction, but noted that nighttime incontinence is problematic (as high as 30%). Long-term follow-up is critical, with special attention to potential acid-base imbalance, ascending infection, and poor renal function. Also, there is an associated

risk of intestinal malignancy, although intestinal malignancy has not been noted in the Eritrean population on which Dr. Morgan reported.

Participants recognized the need to discuss ethics from a clinical perspective. According to Prof. Oladosu Ojengbede, a multidisciplinary management approach for women with fistula deemed incurable is long overdue; because standard definitions and treatment protocols do not exist, it is understandable that many providers are forced to “fly blind.” Prof. Ojengbede suggested that clinical guidelines would help to shed light on the situation.

Prof. Gordon Williams shared the experience of the Hamlin Fistula Hospital, Addis Ababa, noting that more than 150 women at that facility have undergone ileal conduit procedures that have resulted in a much-improved quality of life. Because complication rates are not insignificant, these procedures should only be performed in centers that can provide close, long-term follow-up care and treatment. In addition, because the appliance used in the procedure is costly, the sustainability of the technique is limited. And yet use of the appliance is mandatory because, if the appliance is not used, the only change in the woman’s situation is the placement of the hole: from the vagina to the abdomen. Prof. Williams also shared an 18-question memory aid that helps providers as they inform women about the procedure.

In the absence of a standardized model, Prof. Serigne Magueye Gueye proposed four questions (“the 4 Ws”) to inform clinical care.

Table 1. Assessing Fistula Deemed Incurable: The Four Ws

Who	Who is competent to decide whether the fistula is incurable?
When	When do clinicians conclude that a fistula is incurable?
Why	<i>Primary:</i> The lesion is severe enough to make the fistula irreparable. <i>Secondary:</i> The fistula is irreparable because of lack of expertise in a reasonable timeframe and at an appropriate geographic location.
What to do	Discuss options with the woman (e.g., urinary diversion, nonsurgical care, supportive care)

Some participants suggested an additional W: Where or at what level of the health system can PFRD cases be managed?

Gaps and Barriers

Clinical constraints and barriers include the following:

- Lack of awareness about PFRD among medical professionals, paramedical personnel, and the community (as a result, patients are not identified)
- Poor referral and communications systems within and external to the clinical setting
- Lack of a patient registry
- Inadequate credentialing, training, and clinical mentorship for providers
- Difficulty retaining trained personnel
- Lack of postoperative supportive care in the short-, medium-, and long-term

Health systems need a framework that describes the minimal requirements for each level of the system; facilities could use such a tool to help them determine if they are capable of tackling difficult cases.

Programmatic Perspectives

Participants discussed programmatic perspectives above and beyond clinical issues. Prof. Sayeba Akhter and Dr. Sohier Elneil outlined key concepts for discussion.

Considerations

In countries with scarce resources and cash-strapped health systems, there is often no obvious “owner” of incurable fistula or recognition of what or who can organize the necessary services. According to Dr. Sohier Elneil, conceptualizing incurable fistula as a chronic disease might be helpful when talking with governments because policymakers understand this language and consider themselves responsible for other chronic conditions in their populations. Like other chronic diseases, incurable fistula has a profound impact on quality of life, family life, social life, and ability to work. Similarly, it requires self-care and management and could benefit from approaches used successfully for other chronic diseases (e.g., case management for diabetes).

Dr. Mark Morgan noted that the International Classification of Diseases does not track obstetric fistula; thus, there is no ongoing monitoring of women with the condition or any sense of responsibility for monitoring them. “What is not counted does not count,” Dr. Morgan noted; as a result, obstetric fistula suffers from “invisibility.” Ms. Gillian Slinger added that if incurable fistula had an ICD number and were notifiable, this would facilitate gathering information about the condition and might provide impetus to better serve affected women.

There was much discussion about a program’s responsibility to share both surgical and nonsurgical options with the woman before she decides on a course of treatment. (See more below in the section on ethical perspectives.)

Prof. Sayeba Akhter raised an issue that programs must consider upfront: reintegration for women whose fistula is deemed incurable. The goals of a woman with incurable fistula may differ from those of a woman whose fistula is successfully repaired. Reintegration begins with case identification, counseling, and preparation for surgery; it continues through pre- and postoperative care. Linkages with other organizations and groups are essential as the woman prepares to enter or reenter a community.

Reintegration is a “two-way street”; both women and the communities they enter or reenter require preparation and support. Dr. Gloria Esegbona provided an illustration of “fistula football”; FFN has supplied soccer balls to communities as a way of engaging men and leading them to discuss obstetric fistula.

Gaps and Barriers

Professionals working in fistula care need to conduct rigorous research to determine the psychosocial dimensions of PFRD. Dr. Joseph Ruminjo noted that the psychological

conditions associated with PFRD are as complex as the physical conditions; furthermore, the fistula care community needs a basis of evidence on which to understand how best to assist women. Several providers cited profound depression as an important issue; programs lack an understanding of how to provide better and more appropriate care for this condition.

Counseling services, if they exist at all, are often inadequate in programs trying to meet the needs of women with PFRD, including reintegration. Improving communication about self-management and care, beginning with informing women about nonsurgical therapies, is a critical need. If a woman is to be able to care for herself, programs must be able to answer her questions and discuss relevant products (such as pads) and practices (such as hygiene).

Programs also need to forge links with other social services in the community, especially since women with PFRD often need to care for themselves economically.

Ethical Perspectives

While the topic of ethics was woven throughout the two-day meeting, Dr. Steven Arrowsmith, Prof. Oladosu Ojengbede, Dr. Jay Smith, and Ms. Mary Nell Wegner specifically addressed ethical concerns. The speakers drew on two classic works on bioethics^{4 5} and noted how they might be used when working with women. (See Appendix D for a list of other important literature in ethics.)

Considerations

Women with PFRD are usually extremely poor, have additional health concerns beyond obstetric fistula, have not had the opportunity for formal education, and may or may not have children or a partner/husband. Many of them have had repair surgery that was not successful.

This patient profile and the context in which the woman lives often make the process of informed decision making complicated and difficult; the provider may now know if he or she has been successful in helping the client make an informed decision. Dr. Arrowsmith shared one innovative technique from Niger; a facility in that country engages a woman whose fistula was repaired to act out her experiences living with fistula, interacting with the health care system, and making her decisions about treatment. As she performs in front of women considering surgery, she encourages potential clients to ask questions both of her and of the provider.

Women with fistula deemed incurable are, by definition, survivors. They have endured a difficult and traumatic childbirth; their priorities and ways of dealing with problems may differ from those of the clinician. Women with PFRD are not just passive victims. Their experiences and viewpoints must be central to the communication between provider and client.

⁴ Beauchamp, T.L., and Childress, J.F. 2008. *Principles of biomedical ethics*, 6th ed. New York: Oxford University Press.

⁵ Jonsen, A.R., Siegler, M., and Winslade, W. 2010. *Clinical ethics: A practical approach to ethical decisions in clinical medicine*, 7th ed. New York: McGraw Hill

Dr. Lauri Romanzi noted that fistula care programs can learn from other public health communities that have successfully liaised with community-based resources to obtain services for clients with polio, leprosy, and other conditions.

The group discussed the need to provide a safe space, preferably outside the clinical environment, where the woman can discuss her options. For instance, she may talk with women who have had surgery similar to what she is considering or who have chosen not to have surgery. Providers should not, as Ms. Gillian Slinger noted, choose the “appropriate” surgical option for her. Although the survey distributed to participants before the meeting mentioned the possible need for “charity care” during follow-up and reintegration, Dr. Joseph Ruminjo cautioned that there is a fine line between such care and disempowering the woman who needs assistance.

Ms. Wegner noted the foundational work of Beauchamp and Childress around the four principles of bioethics: autonomy, beneficence, nonmaleficence, and justice. Several tools have been developed to help providers and administrators with complicated ethical decisions about client care (some of them include a question or two designed to elicit the client’s perspective); likewise, there are several lists of patient rights. Yet there is no known tool specifically designed to help a client decide from among health care options. For this reason, she proposed a box model (Figure 1) based on the work of Jonsen, Siegler, and Winslade and composed entirely of boxes from a client’s perspective.

Figure 1. Meeting the Needs of Clients with Persistent Fistula-Related Disorder: A Box Model

<p>Functionality</p> <p>Will the client be able to:</p> <ul style="list-style-type: none"> • Work again? • Do daily chores? • Care for children or others? • Have sexual relationships? • Bear children? 	<p>Aesthetics</p> <ul style="list-style-type: none"> • Will anything about the client’s appearance be so different that her self-image might be threatened? • Will aspects of the proposed care be unacceptable to the woman, her family, or the community (e.g., needing to void stool through the abdomen, needing to void urine and stool through the same hole)?
<p>Sequelae Management</p> <ul style="list-style-type: none"> • What are the possible complications from the chosen intervention • What are the management options? • What is the likelihood of chronic pain, infection, bone loss, intestinal cancer? • Will the client be able to come for regular checkups? • Can the facility manage follow-up care? 	<p>Social Acceptance</p> <ul style="list-style-type: none"> • What is available to support a client’s desire and ability to fit back into the community? • If the woman chooses surgery, can reintegration challenges be anticipated before surgery? • If the woman chooses not to have surgery, what are the reintegration challenges she is likely to face?

Gaps and Barriers

Participants identified several gaps related to the ethical perspective:

- The need for tools and methods to assess an individual woman's needs in relation to the options available
- The need for a registry that captures information about clients' long-term health needs after diversion or other surgery
- The need for a registry that captures information about clients' long-term health needs for women who choose not to have surgery.
- The need for a clinical review board within a facility or at a referral center to help providers manage extremely complicated cases of fistula (guidelines would specify the composition of the board and the qualifications of its members)
- The need for a model or framework that a client could use to understand her options and make a decision about treatment (Figure 1 might serve as the basis for developing such a model)

Five Areas of Emerging Consensus

As the participants discussed the four perspectives (the client, the clinical provider, the program, and ethical issues), consensus emerged in five areas.

A Paradigm of Possibility

A term such as *incurable* denotes finality when, in fact, the injury might be able to be successfully repaired at another facility or at another time. To transform the culture of “Never” to one of “Not yet,” new terminology is needed. The group proposed two terms:

- *Persistent fistula-related pelvic-floor disorder* (PFRPFD)
- *Persistent fistula-related disorder* (PFRD), the more inclusive term

While both of these terms have some limitations, a registry of such cases would both help determine if the terminology is useful and elucidate the types of solutions that are needed.

Conducting Social Science Research

Participants called for social science research to complement clinical research in order to better understand the experiences of women with PFRD. One key research area is the psychological aspects of living with PFRD; studies would need to be structured in such a way as to assist providers and facilities working with these women.

Engaging Important Stakeholders

Obstetric fistula remains unnoticed by many key stakeholders within governments, policymaking bodies, and clinical institutions (e.g., the committee for the International Classification of Diseases). The condition is not yet widely recognized as an important reproductive health morbidity, much less an issue of equity. Mechanisms are needed to engage stakeholders.

Professional associations and ministries of health play a central role in developing standards and guidelines and carrying them forward. They are the bodies best able to support their members, providers, and facilities with needed resources. While keeping a focus on the critical need for women to be able to make an informed choice, their guidance will help providers support women through a series of conversations about available therapeutic options, ultimately leading to the best choice for individual clients.

Collecting Critical Data

More data need to be gathered on several fronts to create a basis of evidence to inform programming and practice. An information base or patient registry could begin to track the long-term health outcomes for women and provide important information for clients, providers, and programs. These data should include the number of women with PFRD, the types and number of surgeries done, audit results, follow-up care, and outcomes. Information about providers (e.g., their training, the types and number of procedures they perform) would help to inform the credentialing process. Finally, standard terminology to

describe the skill level of providers based on qualifications and experience would help facilities and women know more about provider competence.

Empowering Women

To consider the needs of a client through her eyes and to help her make her own informed decision, the provider must possess several skills and abilities. The situation becomes even more complex when the provider and client speak different languages. Several resources would be helpful: a standardized tool that outlines issues to discuss with the woman, management guidelines, and standards of care for women with PFRD. Women will also need clear information about self-care and assistance with reintegration.

Recommendations

1. Share the term *persistent fistula-related disorder* with the larger community of fistula stakeholders for their review and feedback. Ask if it is important to drop the phrase *pelvic floor* from terminology in order to capture even those iatrogenic and rape-related fistulae that do not involve the pelvic floor.
2. Ask donors to fund social science research about PFRD (to shorten the research-to-practice time span, it may be possible to link researchers with organizations that can act on the findings).
3. To capture the attention of policymakers, conceptualize fistula as a chronic, noncommunicable disease.
4. Work with the ICD committee to categorize obstetric fistula as a notifiable or reportable disease. Once this is done, a tracking system can be implemented to count the number of cases, including those classified as PFRD.
5. Commission the design of a patient registry for PFRD cases, and pilot test it in several facilities to determine the feasibility of collecting long-term data about women with PFRD. Collaborate with a community group to pilot test the registry. Include reintegration as part of registry information.
6. In collaboration with key partners in the obstetric fistula community, convene a small technical working group to develop a credentialing process for providers. The group would also address standard terminology to describe skill levels for working with women with PFRD, management guidelines, standards of care, and credentialing for sites.
7. Review existing tools designed to help women make decisions about therapeutic options (e.g., memory aids, counseling curricula, box model, drama). In collaboration with staff at facilities serving women with fistula, compare existing tools and explore what helps women to make informed decisions about care.

Conclusion

Among the underserved population of women with obstetric fistula, those with PFRD stand apart: they are the group about whom the least is known. The literature is scant; the resources insufficient; and the need for increased focus great.

Providers working with these women do not have the benefit of standardized definitions—much less guidelines, standards, and protocols. Developing such tools based on data is a critical first step to begin to standardize evidence-based care. These resources could also help concerned professional associations support their members.

At the same time, it is imperative that the obstetric fistula community take a close look at how women can be empowered and given voice in decisions about care.

While prevention is undoubtedly the most important factor to stem the tide of women developing obstetric fistula, those already living with this condition have been robbed of hope for far too long; it is time to create a culture of possibility.

Appendix A: Meeting Participants

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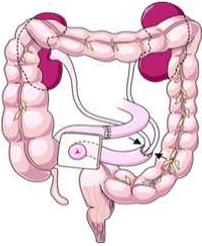
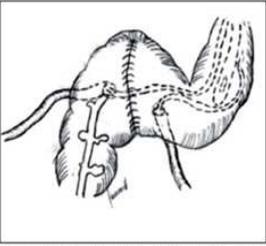
Appendix B: Meeting Agenda

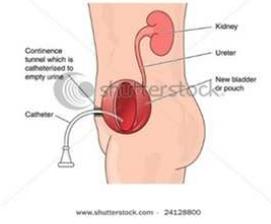
Day 1: Monday, September 19, 2011		
Chairperson: Prof. Serigne Magueye Gueye		
Time	Activity	Presenter
8:30–9:00.	Registration	Ms. Celia Pett Ms. Bethany Cole Ms. Dana Swanson
9:00–9:30	Opening Remarks <ul style="list-style-type: none"> • EngenderHealth, Fistula Care Project • Harvard Humanitarian Initiative • U.S. Agency for International Development Introductions	Ms. Karen Beattie Dr. Julia VanRooyen Ms. Erin Mielke Ms. Karen Beattie
9:30–10:15	Purpose of the Meeting <ul style="list-style-type: none"> • Rationale • Objectives • Expectations • Review of the Agenda 	Dr. Joseph Ruminjo
10:15–10:30	Logistics	Ms. Celia Pett
Coffee Break		
10:45–11:30	Improving Quality of Life: Client Perspectives on Their Needs and How Well They Are Being Met Facilitated Discussion: Perspectives from Other Country Experiences	Dr. Gloria Esegbona
11:30–12:30	Meeting the Needs of Women Whose Fistula Is Deemed Incurable: What Are the Challenges? Literature Review and Results of Premeeting Survey	Dr. Steven Arrowsmith Dr. Joseph Ruminjo
Lunch Break		
Chairperson: Dr. Lauri Romanzi		
1:30–2:30	Ethical Perspectives on Meeting the Needs of Women Whose Fistula Is Deemed Incurable Panel Discussion	Ms. Mary Nell Wegner Dr. Steven Arrowsmith Prof. Oladosu Ojengbede Dr. Jay Smith
2:30–3:00	Clinical Perspectives on Meeting the Needs of Women Whose Fistula Is Deemed Incurable <ul style="list-style-type: none"> • Continuum of Care: What Are the Available Clinical Options, Their Benefits, and Challenges? 	Prof Serigne Magueye Gueye
Coffee Break		
3:15–4:45	Urinary Diversions <ul style="list-style-type: none"> • Overview • Country Experiences <ul style="list-style-type: none"> ○ Eritrea ○ Ethiopia ○ Niger 	Dr. Julia VanRooyen Dr. Mark Morgan Prof. Gordon Williams Dr. Sanda Ganda
5:15–6:30	Reception	

Day 2: Tuesday, September 20, 2011		
Chairperson: Prof. Oladosu Ojengbede		
Time	Activity	Presenter
9:00–9:20	Recap of Previous Day	Dr. Joseph Ruminjo
	Housekeeping Issues	Ms. Bethany Cole
9:20–10:00	Programmatic Perspectives on Meeting the Needs of Women Whose Fistula Is Deemed Incurable	Dr. Sohier Eneil
10:00–10:30	Reintegration	Prof. Sayeba Akhter
Coffee Break		
10:45–12:30	Working Group Discussions	
Lunch Break		
Chairperson: Dr. Sohier Eneil		
1:30–2:45	Feedback from Working Groups	
Coffee Break		
3:00–3:20	Professional Associations and Ministries of Health: Considerations in the Development of Standards and Guidelines for Care	Prof. Gordon Williams
3:30–4:00	Summary of Meeting Discussions	Ms. Mary Nell Wegner Dr. Julia VanRooyen
4:00	Thanks and Meeting Closure	Ms. Karen Beattie

Appendix C: Treatment Options for Women with Persistent Fistula-Related Disorder

METHOD	ADVANTAGES	DISADVANTAGES
Hygiene and exercise options		
Incontinence products and personal hygiene counseling  <i>The Jika pad (developed by Dr. Gloria Esegbona; image reproduced with her permission)</i>	<ul style="list-style-type: none"> • May be perceived as less stigmatizing than urinary diversion with stoma • Prototype Jika pads: reduced discomfort, leakage, and smell. May have income-generating potential for women (women can produce sanitary pads and infant diapers using Jika materials). 	<ul style="list-style-type: none"> • Incontinence pads: expensive • Conventional pads made from rags: uncomfortable, unhygienic, smelly; such pads contribute to dermatitis, excoriation, and ulceration
Pelvic floor exercises	<ul style="list-style-type: none"> • If well taught and adhered to, can be a useful adjunct to other treatment options 	<ul style="list-style-type: none"> • Limited success in reducing incontinence • Limited access to specialist physiotherapy services • Generally poor adherence to exercise regime
Vaginal dilators	<ul style="list-style-type: none"> • Can alleviate vaginal stenosis and help women to resume sexual intercourse 	<ul style="list-style-type: none"> • May not be readily available • May require repeated use
Nonsurgical treatment options		
Periurethral injections		<ul style="list-style-type: none"> • Need to be given frequently • Expensive • Not well studied in this population
Urethral plugs	<ul style="list-style-type: none"> • Can be used even for severe incontinence 	<ul style="list-style-type: none"> • May be expensive • May not be readily available • Variable risk of infection • Occasional displacement into bladder

METHOD	ADVANTAGES	DISADVANTAGES
Surgical options: Conduit diversion		
<p>Ileal conduit</p>  <p>(Source: Sudakoff G S et al. <i>American Journal of Radiology</i> 2005; 184:131-138)</p>	<ul style="list-style-type: none"> • Technically simple 	<ul style="list-style-type: none"> • Requires abdominal stoma • Often culturally unacceptable • Requires expensive ostomy supplies and follow-up (usually financially and logistically impossible in low-resource settings)
Surgical options: Continent diversion		
<p>Ureterosigmoidostomy</p>  <p><small>Figura 5. Neovejiga terminada con los tutores ureterales y sonda rectal in situ.</small></p> <p>(Source: Castillo O. A. <i>Laparoscopic cystectomy and recto-sigmoid pouch creation. Report of one case. Rev Chil Cir</i> v. 60, n 6 December 2008; 552-556. Reproduced with author's permission.)</p>	<ul style="list-style-type: none"> • Avoids stoma • Not technically difficult • Does not require catheter or need revision 	<ul style="list-style-type: none"> • Requires intact anal sphincter • Often culturally unacceptable • Requires life-long follow-up due to potential long-term side-effects/risks, including metabolic acidosis, urinary tract infection, ureteral stenosis, urinary calculi, hydronephrosis, bone demineralization, nocturnal incontinence, and intestinal cancer (intestinal cancer is unproven in the African setting)
<p>Mainz II pouch (modification of this ureterosigmoidostomy)</p>	<ul style="list-style-type: none"> • Theoretically easy, open ureteral anastomosis compared to ileal conduit • Less nocturnal incontinence, infection, and ureteral stenosis compared to classic ureterosigmoidostomy 	<ul style="list-style-type: none"> • Same as ureterosigmoidostomy

METHOD	ADVANTAGES	DISADVANTAGES
<p>Mitrofanoff procedure</p>  <p>(Source: www.shutterstock.com)</p>	<ul style="list-style-type: none"> • Avoids stoma 	<ul style="list-style-type: none"> • Technically complex • Requires catheter • Often culturally unacceptable • Frequently requires revision resulting from catheter blockage
Other surgical options		
<p>Fibromuscular sling (with or without urethral plication)</p>  <p>(Source: NIH)</p>	<ul style="list-style-type: none"> • Not technically difficult 	<ul style="list-style-type: none"> • May not achieve good continence (preliminary results, 2011, from a randomized control trial at Addis Ababa Fistula Hospital: no benefit)
<p>Bladder augmentation</p>	<ul style="list-style-type: none"> • Augmentation with ileum to restore capacity: not technically difficult 	<ul style="list-style-type: none"> • Requires self-catheterization for some women; can be taught and does not require extensive supplies
<p>Kock pouch urostomy, trigonosigmoidostomy</p>	<ul style="list-style-type: none"> • Variations in diversion favored by those with special skills 	<ul style="list-style-type: none"> • Technically difficult

Appendix D: Literature Search Citations by Theme

CLIENT PERSPECTIVE

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